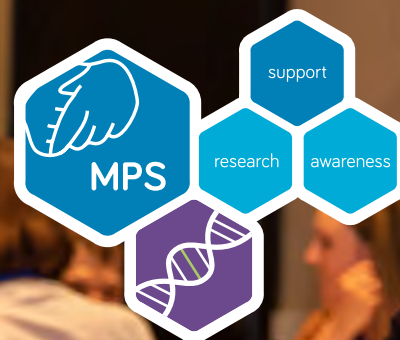


RESEARCH | AWARENESS | SUPPORT



# Impact Report

2019/20

# A world no one expected



Bob Stevens  
Group Chief Executive

Like many of you I have been shielding along with my family and coming to terms with online shopping and home haircuts!!

Here at Team MPS we have been adapting too. Although we have all been working from home we have reached out to approximately 500 families to offer support and to work with them on resolving the many day-to-day issues in a COVID-19 world. We have a dedicated area on our website for COVID-19 with many useful resources, interesting information and webinars. We have also been working with the clinical centres and NHS commissioning on how services need to adapt in the immediate future and this work is ongoing.

For the near future we will be unable to offer face-to-face meetings in person but instead we have been offering virtual meetings and this has proved very successful. We held our first online quiz and hope to have more fun and games over the next few months. Our young adults section "Rare Voices" continues to gain momentum and we encourage all our young people to give this a try and have your voices heard.

We are also looking at how we can help strengthen mental health services for our community in the future and work is being done to secure resources for this much needed extra support. As you will have seen many of our events for 2020 have been postponed but they will be back with a bang in 2021. In the meantime, there will be some virtual events so watch this space for news on this.

Of course, much like other charities, this change in demand for our services has placed a significant burden on our finances. Our helpline is busier than ever, requiring our support team's dedication round the clock, but thanks to the generosity of our supporters we are able to keep providing this vital service and transforming the lives of people living with MPS, Fabry and related diseases. Without your support and donations, we simply could not provide this service.

Raising funds for the MPS Society in a virtual way is a great chance to try something new, helping your mental health and helping us to bridge the funding gap. The fundraising team are always on hand to offer you any fundraising tips and advice, I know they would love to hear from you.

I hope you enjoy reading our first newsletter in this format, which will be sent to you annually. As always, we value your feedback and would love to know your thoughts on our 'new look' newsletter. You can contact the communications team with any thoughts.

Finally remember the team is always here to support you and as a community, we will get through this. We may be rare but we are all in this together.

Warmest wishes,  
Bob

“Keep up this good work and explore opportunities for people with all conditions. Help us live our best life.

MEMBER FEEDBACK

WE MADE REGULAR CONTACT WITH

1500

FAMILIES ACROSS THE COUNTRY

## OUR IMPACT IN 2019

# 133



HOME VISITS TO FAMILIES WE SUPPORT CHECKING IN AND OFFERING ADVICE

LAUNCHED GRIEFCHAT ON THE BEREAVEMENT SECTION OF OUR WEBSITE



# €100K

OF FUNDS RESTRICTED FOR RESEARCH

# 45

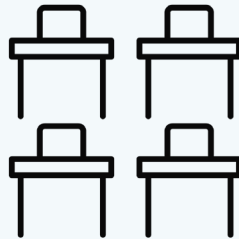
VISITS TO EXPERT CLINICS HELD AT LEADING CLINICAL CENTRES ACROSS THE UK

# 25

VISITS TO NEW MEMBERS OFFERING FRIENDLY ADVICE AND A LISTENING EAR

# 3913

PEOPLE VISIT OUR FACEBOOK PAGE EACH WEEK



# 23

TALKS IN SCHOOLS AND CARE HOMES INFORMING STAFF ABOUT THE DISEASES

# 1922

FOLLOWERS ON TWITTER



Olivia (MPS IV Morquio) set up a Facebook fundraiser for her 21st birthday. She says: "Starting the trial for Vimizim at GOSH in 2010 has done wonders for my health and it's one of the main reasons I could celebrate my 21st in the sun with friends and family. I set up a Facebook fundraiser for the MPS Society and raised £375. The work the MPS Society does is incredible and I'm forever grateful." Happy 21st Olivia!

ON AVERAGE

# 2589

PEOPLE VISIT OUR WEBSITE EACH MONTH





## FAMILY EVENTS



“Over the years the MPS Society has connected us with other families through their family events”

For Maddison, and many other children with MPS III Sanfilippo, the future is not so bright.

“It was such a shock when she was diagnosed with this disease we’d never heard of before. Since being told, we’ve had every possibility going through our heads about what could happen to her. She’s such an active girl at the minute, hyperactive if anything, so it just doesn’t seem real that this will happen to her.

“The MPS Society have been an invaluable support to Maddison and our family, something we will be forever grateful for. Over the years the MPS Society has connected us with other families through their family events and they have connected us with medical professionals through their conferences. The world of Sanfilippo Syndrome would be much more isolating if it wasn’t for the support and services that they offer.”

Shelly, Maddison’s Mum

## Focus on Fabry conference

“The speakers were excellent, pitching it exactly right for the delegates. It was a friendly and supportive environment in lovely surroundings.”





## Weekend of Hope and Remembrance, October

“Wonderful event where we could openly talk about our children, without having to explain MPS. A chance to laugh and cry together without explanation.”



## Treats For All

“Romy’s mobility has sadly worsened and so she has now moved into a downstairs room which is also next to the bathroom, making life a lot easier for her. We were delighted that Romy was lucky enough to receive the Hobbycraft voucher to keep her entertained during lockdown. Thank you for such a lovely treat.”



## Lapland UK

“Thank you so very very much for a wonderful day. We’re all still talking about it and giving each other the special elf wave.”

“It was incredible. We loved all of it.”

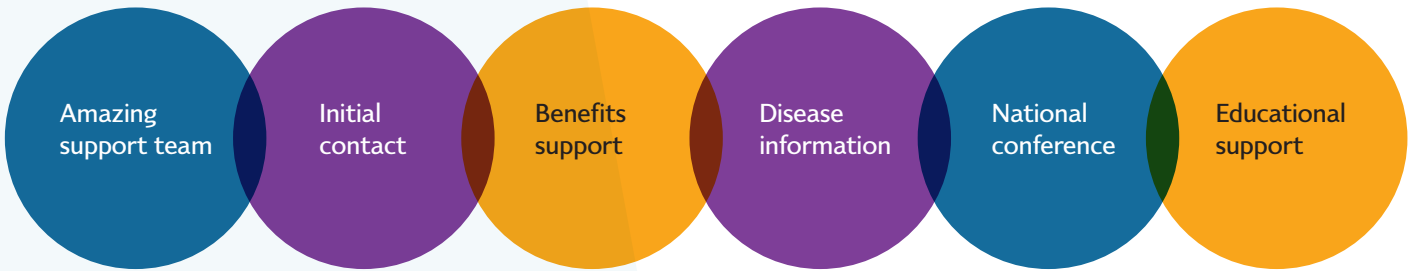




## HOW WE'RE IMPROVING

# You said...we did

To make sure we are constantly reviewing and improving our services we invite feedback all the time. This year we reviewed our core service provided by the Support and Advocacy Team. This is what you told us that we're doing well:



This is where you think we can improve:

**Greater emotional support for members and their families and friends**

We are finding new ways to raise funds so we can continue to invest in the Support and Advocacy Team and their development. We identified future support needs with a thorough review and asking our community for feedback and will introduce these changes over 2020/2021.

**More interactive presence on social media**

We are looking for more opportunities to connect in a way that suits you and have already introduced online coffee and chat sessions and collaborative webinars. We are also investing more time and energy into gathering and creating video content and working with other organisations to feature patient stories through film.

**Ensure inclusion of all conditions and ages**

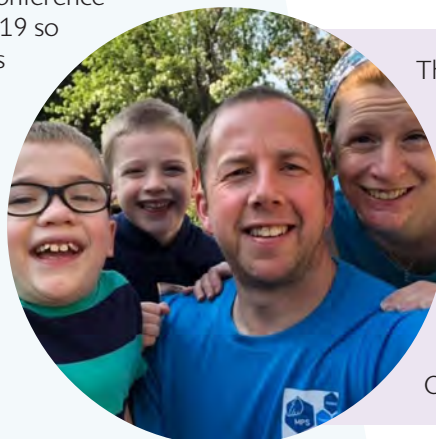
We launched Rare Voices, the young adults' discussion group aimed at tackling those issues that specifically affect young people with MPS, Fabry and related diseases. We are expanding the support we offer to bereaved families, collaborating with other organisations including GriefChat to signpost families who may need support from a trained bereavement counsellor. For the first time we held a separate Fabry conference alongside the MPS National Conference in 2019 so all members could get the most from experts and peers.

**Increase awareness of what support is available**

We are continuing to raise our profile to reach more affected people and help them find the information they need. Our website was relaunched in 2019 and is constantly being reviewed so we can improve the way we present information. This includes updating the Advocacy and Support Team pages to highlight the services that are available and offering better signposting. We are also updating all our booklets on disease and treatment information alongside those pages on the website.

**Expand information on treatment options and clinical trials**

We are reviewing the way we share news and information on the latest treatments and trials to make sure you are always up to date. We have also launched the Clinical Scientific Advisory Committee to allocate funds for research projects, the first was awarded to Dr Simon Heales at Great Ormond Street Hospital to investigate new technology that could identify MPS related diseases. We are committed to keeping MPS, Fabry and related diseases on the public health and economic agenda by engaging with and influencing government and policy makers, including our ongoing fight for access to treatments.



The Brown family took on the 2.6 Challenge and raised well over £2,000 by completing a marathon in their garden. Sam (MPS IV Morquio) completed the final lap and says: "The MPS Society means a lot to me because if it wasn't for them I wouldn't have my Vimizin which means I wouldn't be able to do things like this, running the final lap in our 2.6 Challenge." Well done family Brown!

## HOW WE ADAPTED DURING COVID-19

# During the COVID-19 lockdown period we have been...

...actively contacting all our members to see how they are by phone, email or video call.

...regularly updating information on our website and social media, including specific guidance for those with an inherited metabolic disease making sure our members continue to feel part of a supportive community.

...delivering a mixture of video content via webinars and video lectures on relevant topics from health professionals, other patient organisations, Society members and our own staff.

...working closely with the NHS to prepare homecare advice and resources including a 'Questions and Answers' pack for caring for children at home.

...collaborating with expert clinical centres to provide the most up to date information and to share as much knowledge as possible.

...facilitating a regular online, informative session with expert speakers purely for our young people as part of our new "Rare Voices" group.

...providing vouchers for a Treat for All initiative so members and their families can enjoy a bit of downtime together doing whatever they enjoy.

Our Support and Advocacy Team have continued to provide all the usual support to members to make sure they are receiving the care they need and are coping. We will continue to provide and adapt our vital support services to our community throughout the pandemic and beyond.

IN 2019 WE MADE

# 103

VISITS TO PROVIDE SUPPORT WITH BENEFITS, HOUSING AND SOCIAL CARE



Our lovely corporate partner, Liquidnet, arranged a virtual bake off to keep their team motivated during lockdown. Fifteen team members took part along with Becky, our Fundraising Officer. The team had loads of fun making delicious Prosecco and Strawberry Cupcakes and raised almost £400. They are now all expert bakers with excellent piping skills and are already planning their next event, which will be a 24 hour bike ride. Thank you Liquidnet!

We are making good progress on our three-year strategy which you can read at [mpsociety.org.uk/vision](https://mpsociety.org.uk/vision). Through all our work we will uphold our core values:

Patient first

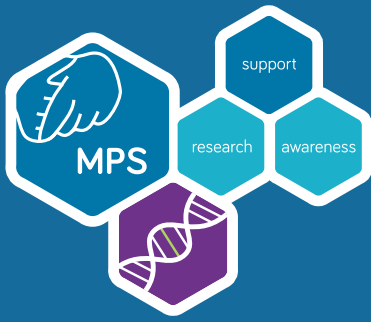
We will always put the patient first

Open and transparent

We will always be open and transparent

Speak out

We will always speak out on issues that affect our community



# Together we can transform lives

Thank you to those who shared their photos and stories for this newsletter. Please keep telling us about your life with MPS, Fabry or related diseases and your fundraising events. We try to share as many stories as possible on our website and we'd love to hear yours.

Help us to achieve our future plans and keep supporting everyone affected by MPS, Fabry and related diseases through a regular gift, taking part in one of our many challenge events, getting your company involved or volunteering your time.

## Contact us for more information:

[fundraising@mpssociety.org.uk](mailto:fundraising@mpssociety.org.uk)  
[mpssociety.org.uk/donate-now](http://mpssociety.org.uk/donate-now)

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